



# The Research Connection

The Psychosocial & Nursing Advisory Board to  
the New Jersey Commission on Cancer Research

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Number 1

The Joint Psychosocial & Nursing Advisory Group to the New Jersey Commission on Cancer Research (NJCCR) was appointed to advise the NJCCR of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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## Caregivers of Cancer Patients – Challenges and Issues

by

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Caregivers may derive satisfaction from helping and caring for a cancer patient either by choice or obligation. However, the role of caregiver is often physically and emotionally draining especially if it is involved over long periods of time. Studies have reported that spouses can actually suffer more anxiety than their loved ones with cancer. Gaynor(1990) discovered that one-third of hospital admissions were for reasons directly related to caregiver health.

Those who are providing care may benefit from joining a caregiver support group. In addition to offering useful information, such groups provide a unique forum for caregivers to come together and share their feelings in a supportive environment. Participating in a support group can help manage stress, enable them to exchange experiences, and improve their skills as a caregiver.

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Caregiving is probably only one of a number of conflicting demands on the caregiver's time. Defining priorities, acting accordingly, turning to other people for help such as family, friends, and neighbors are strategies to relieve the stress.

The caregiver must take care of their own needs. Caregivers must be at their best if they are to provide the best care. Taking time off to continue pursuing activities that are enjoyable or that provide stress relief, exercise, eating right, and getting plenty of rest need to be encouraged. The message to the caregiver needs to be that their self-care is just as important as caring for the patient.

### **Developmental Aspects of Psychological Distress in Adolescents with Cancer**

by

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Numerous studies indicate that cancer is a significant threat to the family system and have assessed individual, sibling and parental coping responses (Koocher and O'Malley, 1981; Krisjanson & Ashcroft, 1994; Thoma, Hockenberry, Eaton & Kemp, 1993). Studies of the long-term sequela for parents of children who have survived cancer are sparse (Van dongen-Melman et al., 1995). While many studies support that parents have many concerns and worries regarding their children after treatment (Koocher & O'Malley, 1981; Martinson & Cohen, 1988; Van dongen-Melman et al., 1995), other studies revealed no differences in anxiety, depression or parental distress between parents of cancer survivors and healthy controls (Kazak & Meadows, 1989; Speechley & Noh, 1992). Speechley & Noh (1992) identified the strong role that social support has in influencing adverse psychological consequences in parents of children with cancer. In their study, among parents who reported low social support, parents of survivors of pediatric cancer experienced greater distress than those parents with healthy children. Additionally, parental needs for social support may differ based on gender, as mothers report perceived social support as more important than fathers (Elliott-Brown & Barbarin, 1996).

As a sequela to living through the experience of having a child survive cancer, substantial research is being focused on investigating factors related to post-traumatic stress disorder. Evidence exists that survivors of childhood and adolescent cancer do manifest symptoms of posttraumatic stress, yet increased incidences have been reported among parents and siblings (Kazak, et al, 1997). As a result of developmental processes, how children and adolescents psychosocially respond to illness remains dramatically different than adults.

While psychological distress is a frequent sequel to cancer, methodological concerns in this age group exist. In the initial investigations of psychosocial functioning in pediatric cancer, it was believed that all children and adolescents with cancer would manifest psychological disturbance and studies utilized instruments measuring psychopathology. Recent studies however, consistently indicate that adolescents with cancer do not inevitably experience psychopathological symptoms, but are likely to manifest distress in one or more areas of functioning over the course of their illness which may not be included in standardized adjustment measures.

Koocher and O'Malley (1981) in their classic study of long-term survivors of pediatric cancer reported that reaction to the stress of cancer manifests itself in three ways: high anxiety and other psychological adjustment problems as a result of being preoccupied with the fear of recurrence; falsely believing that as survivors, they have gained an immunity to cancer, and lastly, not thinking about it. Other investigators have found that adolescents with cancer tend to function by attending to day to day tasks such as school events, peer social activities and academic work (Zeltzer, LeBaron & Zeltzer, 1984). Both the attitude of not worrying about cancer and the attempt to normalize their lives have been identified as a form of adaptive denial (Katz, Kellerman, & Siegal, 1980; Zeltzer et al., 1984). Koocher (1985) reported that adolescents who believe they are immune to cancer and those who do not think about it, are using adaptive denial to cope with the uncertainty about cancer. Weekes (1989) defines adaptive denial as a strategy that calls for a positive, optimistic outlook in which the person fills his or her mind with daily thoughts and concerns rather than worries about illness (p. 196).

In an investigation of adolescents recently diagnosed with cancer (Neville, 1996), few adolescents manifested levels consistent with a caseness of psychological distress. Interviews revealed that many adolescents demonstrated adaptive denial by expressing the belief that everything would be fine. Discussions with adolescents focused on everyday events, such as proms, graduation, and future activities, which for some may have been likely, but for others given the severity of their diseases were unlikely, and may have represented dreams, hopes and fantasies. Elkind (1985) refers to this as the “personal fable”, a mental construction or story which may not be true, but enables one to go about everyday life without worrying about real life dangers. Among these adolescents with cancer, adaptive denial may have reduced anxiety and depression.

Health professionals frequently witness the defense mechanism of denial, especially during the early stages of a cancer diagnosis. While denial is problematic if it interferes with adherence to treatment, it’s role in protecting the individual (especially the adolescent) when faced with a significant threat is most important and warrants substantially more investigation.

*References for this article are available by contacting the NJCCR at 609-633-6552 or (njccr@doh.state.nj.us).*

## **Living With Cancer: Family Caregivers**

by

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Currently more than 25 million Americans are taking care of loved ones with cancer or other chronic diseases. This “care” includes the provision of 80% of needed homecare services (National Family Caregivers Association). Of these caregivers 82% are female, 71% are married, 47% are 50 years old or older, 54% live with the person they are caring for, and 36% report devoting greater than 40 hours per week to caring for the person with cancer (“Spotlight on National Family Caregivers Month”, November 2003). Caring for loved ones with illness is not a new practice, however as the complexity of care increases and availability of community resources decreases, the burden of care may be experienced as heavier; particularly in today’s

society in which a larger number of households includes two adults working outside the home.

*People Living With Cancer* indicates that 35% of caregivers feel overwhelmed, and that caregivers use prescription drugs for depression, anxiety, and insomnia two to three times as often as the general population. Sixty-two percent of caregivers report that their own health has suffered as a result of their role as caregivers, and 54% report visiting friends and family less often.

Researchers have attempted to identify factors that contribute to a greater likelihood of distress among caregivers. *Agenda*, the newsletter of the Cancer and Young Adult Inc., cites a Dutch study identifying low income, isolation, and a poor relationship with the cancer patient as being the critical factors leading to “negative feelings” among caregivers (*Agenda* July/August ’00, Issue # 73). This study also reported greater (caregiver) role satisfaction among caregivers with less education, and those providing “explicit and continuous” care. In a study of 164 older cancer patients, and the adult daughters caring for them, Dr. Victoria Raveis found that 30% of caregivers reported symptoms of depression (in contrast with 20% of the general population). In this study published in the October 15, 1998 edition of *Cancer*, Dr Raveis identified a number of factors contributing to “resistance to depression” in these caregiver-daughters. Risk of depression was lower in the women who had cited roles beyond that of caregiver (such as spouse, parent, worker), and higher in those who report a “negative view” of care giving. Those daughters who were performing their roles with less sense of filial obligation described less symptoms of distress. In this study education was found to be inversely correlated with depression. Those women with a broader range of care giving responsibilities were found to be less depressed, while caregivers who were physically ill themselves were more likely to develop depression in the context of their care-giving role. Researchers at the University of Michigan School of Nursing found that caregivers often reported higher levels of stress than the cancer patients for whom they cared. (University of Michigan Health System Publications). This study also suggested that women experienced greater distress associated with care giving than did men in similar roles. Laurel Northouse, Ph.D., R.N, Professor of Nursing at the University and the study’s author proposed that women are more likely to experience distress because they are involved in more interpersonal

relationships within the family. She suggests that women are responsible for managing more roles both in the family and beyond it, so that they may experience greater role disruption and distress in the face of illness. Dr. Northouse emphasized that caregivers need to receive support in order to provide support to the patient.

Recognition of the health consequences, both emotional and physical, of taking care of a loved one with cancer has led some researchers to investigate variables and interventions that may reduce caregiver distress. Dr. Patricia Carter of the University of Texas (Austin) School of Nursing studied the relationship between sleep deprivation and risk of depression among family caregivers, precisely because sleep is “a variable amenable to intervention”. In a study published in Cancer Nursing, Carter and colleague Betty Chang of the University of California (Los Angeles) School of Nursing found that 95% of caregivers reported “severe overall sleep problems”. They found that caregiver sleep problems predicted 63.6% of the variance in caregiver depression. (“Sleep Deprivation Increases Risk of Depression in Family Caregivers”).

A 2001 study tested the effectiveness of a 16-week nursing intervention on caregivers of patients newly diagnosed with cancer (Kozachik, et. al Oncology Nursing Forum). This intervention included nine contacts, both in person and via the telephone, on an every-two-week basis. Masters prepared nurses offered the caregivers guidance about symptom management, direction regarding patient surveillance, and education about the disease and its treatment. The availability of and access to community and family

resources were also addressed, and emotional support was provided. At the end of 16 weeks it was found that the nursing intervention was not effective in reducing the level of caregiver depression, when compared with conventional care. Intervention did appear effective in slowing the rate of emotional deterioration among caregivers, and study authors concluded that greater investigation is warranted to determine whether refinements in the timing and duration of intervention may lead to a reduction in caregiver depression.

Raveis and Mesagno explored the role of pet dogs or cats in mitigating caregiver distress (“Pet Ownership as a Protective Factor Supporting the Emotional Well-Being of Cancer Patients and Their Family Members”. Delta Society, 1993). This study of spousal caregivers found that in households in which a pet dog or cat was present, after controlling for other variables, caregivers exhibited less symptoms of depression than spousal caregivers in homes without pets. The authors also noted that caregiver’s perception of the situation better predicted depression than the status of the patient. Perhaps the presence of a pet altered the caregiver’s perception of their situation.

As patients receive a greater proportion of their care in the home, and family members assume greater responsibility for this care, it is incumbent upon us to investigate the impact this trend has both on patients’ well being, and that of their caregivers.

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